

**NAPA -- FACA 2013 Public Comments**  
***(January to March Comments Only)***  
March 20, 2013

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## MARCH 2013 COMMENTS

**DATE:** March 12, 2013

**SUBJECT:** LEAD Coalition recommendations for updates to the National Plan to Address Alzheimer's Disease

Thank you for your bold and thoughtful leadership of the National Plan to Address Alzheimer's Disease. On behalf of the LEAD Coalition and our partners, I am attaching to this message a letter signed by 54 organizations in support of recommendations for your forthcoming 2013 Plan update.

We appreciate the opportunity to contribute to the dialogue and to collaborate on implementing all elements of the Plan.

Respectfully,

Ian N. Kremer  
Executive Director  
Leaders Engaged on Alzheimer's Disease  
<http://www.leadcoalition.org>

ATTACHMENT: LEAD Coalition recommendations for 2013 National Alzheimer's Plan.pdf

<b><i>Available as separate links:</i></b>
LEAD Coalition Recommendations for 2013 National Alzheimer's Plan <a href="http://aspe.hhs.gov/daltcp/napa/Comments/cmtach172.pdf">http://aspe.hhs.gov/daltcp/napa/Comments/cmtach172.pdf</a>

**DATE:** March 8, 2013  
**SUBJECT:** AFA's Time to Build Report

It has come to my attention that AFA's white paper, Time to Build, which contains AFA recommendation's for the revised plan is not listed in the NAPA comments. I thought I had submitted through the NAPA website. Possibly not...

Attached is the report. Can you give me the email I need to ensure it makes it on the public comment page?

Many thanks,

Eric Sokol  
VP, Public Policy  
Alzheimer's Foundation of America

ATTACHMENT: Time to Build Report-12-12.pdf

<b><i>Available as separate links:</i></b>
Time to Build: Action Steps and Recommendations to Update the "National Plan to Address Alzheimer's Disease"

<a href="http://aspe.hhs.gov/daltcp/napa/Comments/cmtach171.pdf">http://aspe.hhs.gov/daltcp/napa/Comments/cmtach171.pdf</a>
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**DATE:** March 7, 2013  
**SUBJECT:** Please Lead for a Cure

I write to you as a fellow Kansan. Both of my parents were diagnosed at the same time in 2009 with Alzheimer's. It breaks my heart to see them slowly slip away. And, there is no respite from this horrible disease because some many all around me are suffering from the disease or suffering from caring for someone with the disease.

I know I don't have to tell you the facts. I just want to implore you to do all you can to lead us to a future without Alzheimer's.

Sincerely,

Judy Roth  
Manhattan, KS

**DATE:** March 5, 2013

**SUBJECT:** My father suffered from Alzheimers and three of us ended up with Cancer.....Please help!

My father was a superhero. He was a star football player in his day, back in the 1940's. He had articles written about him as a pro golfer. He was handsome and strong and loved by everyone. Until Alzheimers took hold of him and never let him go.

My mother was his caretaker, until she ended up with Ovarian Cancer. Then my sister stepped in to care for both of them, until she ended up with cancer. I stepped in after that, and I ended up with cancer. Being a caretaker is an unbelievably stressful job, and wears people down. We are prime examples. They are all gone now, taken by their illnesses. I was lucky and survived.

So I ask you, PLEASE help to Strengthen the National Plan to Address Alzheimer's Disease!

Alzheimer's is a deadly and unforgiving disease that affects 5.4 million Americans and costs hundreds of billions of dollars to our country each year. One in seven American workers is, or has been, a caregiver for a loved one with Alzheimer's or dementia. A crisis of this magnitude merits an equally serious response. The National Plan to Address Alzheimer's Disease is a bold and groundbreaking effort that will help beat Alzheimer's by 2025, but it must be strengthened if we are to reach that goal.

The Advisory Council on Alzheimer's Research, Care, and Services met in January and made recommendations to HHS. The Council emphasized the urgent need for greater federal research funding, stronger and expanded support for families and caregivers, and a detailed road map with milestones to advance us towards the ultimate goal: the prevention and effective treatment of Alzheimer's disease by 2025. These recommendations are so critical to the effectiveness of the plan that the Council unanimously approved them.

As the Department updates the national plan, I urge you to ensure that these recommendations are included in the 2013 version. We can beat Alzheimer's, but we need a plan that's aggressive, that ensures we have the resources we need, and that includes a detailed road map to getting to a cure.

Mitzi Spallas  
South Pasadena, CA

**DATE:** March 5, 2013

**SUBJECT:** The upcoming Alzheimer's Disease epidemic

Unfortunately there are a large group of congressmen and senators who oppose spending more money to combat Alzheimer's disease. This group seems to care more about reducing the deficit then supporting efforts to find new treatments for AD. We need to speak in terms they understand. 200 billion dollars a year is what it costs our government and citizens to care/ treat AD. This number is expected to grow to a trillion dollars a year over the next several decades. Supporting efforts to find novel treatments for AD makes economic sense.

Patrick Sullivan  
DVAMC  
Chapel Hill, NC

**DATE:** March 5, 2013

**SUBJECT:** Strengthen the National Plan to Address Alzheimer's Disease

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As the Department updates the national plan, I urge you to ensure that these recommendations are included in the 2013 version. We can beat Alzheimer's, but we need a plan that's aggressive, that ensures we have the resources we need, and that includes a detailed road map to getting to a cure.

<b><i>Available as separate links:</i></b>	
List of the over 4,000 People Who Sent this Form Letter in March 2013	To be added in April 2013

## FEBRUARY 2013 COMMENTS

**DATE:** February 13, 2013

**SUBJECT:** CSWE Comment on the National Plan to Address Alzheimer's Disease

As Nancy mentioned, attached is a letter from CSWE providing additional comment on the National Plan. Please share with the Advisory Council and however else you see fit. Let me know if you have questions.

Warm regards,

Wendy A. Naus  
Lewis-Burke Associates, LLC

ATTACHMENT: CSWE NAPA Comment Feb 2013.pdf

<b><i>Available as separate links:</i></b>
Public Comment on the National Plan to Address Alzheimer's Disease <a href="http://aspe.hhs.gov/daltcp/napa/Comments/cmtach170.pdf">http://aspe.hhs.gov/daltcp/napa/Comments/cmtach170.pdf</a>

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From: Nancy Hooyman

Sent: Tuesday, February 12, 2013 2:26PM

Subject: social work curricular resources on dementia care

When we met in November 2011 at the CSWE Annual Program Meeting, I indicated that I would send you information about teaching materials that support social work students' attainment of competencies in working with persons with Alzheimer's disease (AD) and their families. Since then, I have been contacting social work faculty and asking them to submit such curricular resources. After I review all the submissions to ensure their quality, these materials will be posted on the Gero-Ed Center website (<http://www.Gero-EdCenter.org>), which will ensure their dissemination nationally.

These teaching resources can be categorized as case studies; in-class exercises; media; and course syllabi. Most of the case studies and in-class exercises provide opportunities for students to practice assessment skills. However, field placements or service learning experiences are the most widely used mechanism to prepare students to work with older adults with dementia. Nearly every social work program that has responded to our request for curricular resources has placements with the local Alzheimer's Association, adult day health centers that serve persons with dementia, memory care units in skilled nursing facilities and geriatric assessment clinics. There are also placements that are not in typical geriatric settings, such as students in prison settings working with inmates with dementia, advocating at their state legislatures for more funding for services for persons with Alzheimer's disease, or implementing recreational music as a way to reduce stress for social workers practicing with persons with dementia.

I will update you once we have all these materials categorized on our website. At that point, I hope that you will be able to inform others, including the Geriatric Education Centers, of their



availability. These curricular resources could be readily adapted by other professions and disciplines for teaching purposes to ensure competence in working with persons with AD.

I also understand that Wendy Naus will also be sending you a letter from Darla Spence Coffey, the President of the Council on Social Work Education commenting on the National Plan. We hope that you will be able to distribute that letter to your colleagues at HHS and Advisory Council members. We are most appreciative of your support of social work as a key profession in working with persons with AD and their families.

Nancy R. Hooyman, PhD  
Hooyman Professor of Gerontology and Dean Emeritus  
Co-PI, CSWE National Center on Gerontological Social Work Education  
University of Washington School of Social Work  
Seattle, WA  
<http://www.Gero-EdCenter.org>

## **JANUARY 2013 COMMENTS**

**DATE:** January 14, 2013

**SUBJECT:** January 2013 meeting - comments from Minnesota

I would like to submit the following comments to be shared at the January 14, 2013 meeting on behalf of Jean Wood.

Dear Members of the Advisory Council on Alzheimer's Research, Care, and Services:

On behalf of my collaborators in ACT on Alzheimers, the implementation group for the Minnesota Alzheimer's Plan, the Minnesota Board on Aging and the Alzheimer's Association MN ND, we would like to express our deepest appreciation for the work of NAPA and the recommendations to dedicate \$10.5 million to seed the development of state action plans, restore ADSSP funding to \$13.5 million and fully fund the National Family Caregivers Act. Minnesota using its own private and public resources has not only developed a legislatively approved Alzheimer's Plan but a powerful collaboration that has moved forward to implement the plan. ADSSP funding has been key to this effort as well as enabling Minnesota to implement important evidence-based interventions such as the New York University Caregiver Intervention. Minnesota relies on a network of dementia capable caregiver consultants many funded through the National Family Caregivers program to support Alzheimer's caregivers in the community. Minnesota has dedicated significant state and private dollars to building a dementia capable medical care and community care system of the highest quality. With the national coordination and funding that is being recommended by NAPA our work and that of other states would be greatly magnified and impact many more lives.

Jean Wood  
Director, Aging and Adult Services Division  
Minnesota Department of Human Services  
Executive Director  
Minnesota Board on Aging

Donna Walberg  
Integrated Systems -- Dementia Capability  
Minnesota Board on Aging  
St. Paul, MN

**DATE:** January 13, 2013

**SUBJECT:** Person with Alzheimer's should be on the Advisory Council

While I thank you and appreciate all that you are doing, I find it shocking and appalling that no person with the actual disease that you are discussing is on your council.

I cannot think of another disease where this might happen.

From my extensive experience working with people with dementia who are advocates for themselves and other people with the disease, I know firsthand that the best people from whom to learn about the disease are the people with it.

People in the early and mid stages of the disease are able to communicate in a language that the rest of us can understand (I believe that it's up to the rest of us to learn how to communicate with people who lose the ability to communicate in a way that we understand), and they already appreciate much of the difficulties and challenges faced by people in all stages of the disease. In addition, people with early onset Alzheimer's can report firsthand the unique challenges that they face by losing their jobs, taking on new expenses, and yet in many cases still putting children through college and saving for retirement.

In addition, people with dementia must be given the opportunity to advocate for themselves, as the plans that you are recommending will be impacting them directly. It is their future that you are deciding, and yet they have no direct input into these plans.

While there are many many people with dementia across the USA who are active advocates, standing up and speaking out about dementia, you need look no further than Michael Ellenbogen as a passionate, knowledgeable, and outspoken individual, whose hard work and perseverance is already changing the way Alzheimer's disease is viewed by society in general. Michael would make an excellent addition to the Advisory Council.

Thank you for your consideration,

Laura Bowley,

Mindset Memory Centre

Editor of I CAN! I WILL! Stand Up and Speak Out about Dementia

(<http://www.alz.co.uk/icaniwill>)

Facilitator of A Meeting of the Minds virtual meeting of people with dementia

(<http://www.dementiasupportnetworks.com>)

**DATE:** January 13, 2013

**SUBJECT:** Talking points and Recommendations for Meeting

Attached are my talking points and recommendation for tomorrow's NAPA meeting. I want to make sure they are also in the public record. I look forward to meeting with you and Don afterwards.

Regards,

Michael Ellenbogen

Author of "The Insider's Guide To Saving Money"

<http://www.michaelellenbogen.com>

<http://www.michaelellenbogenmovement.com/>

ATTACHMENT: NAPA 14\_2013\_TalkingPoints.docx

<b><i>Available as separate links:</i></b>	
January 14 Talking Points	<a href="http://aspe.hhs.gov/daltcp/napa/Comments/cmtach164.pdf">http://aspe.hhs.gov/daltcp/napa/Comments/cmtach164.pdf</a>

**DATE:** January 13, 2013  
**SUBJECT:** Comments RE the Advisory Council

As a former caregiver and an ardent advocate in the fight against Alzheimer's, I want to thank you for the excellent work that has been done thus far regarding NAPA. I'm hopeful that this year we will see adequate support and funding to implement your recommendations and turn our shared dream of NAPA and a world without dementia into a reality.

I understand that the Advisory Council consists of at least 22 members and meets quarterly to discuss the efficacy of government programs targeting the needs of individuals and caregivers coping with the consequences of Alzheimer's and related disorders. My request and hope is that the Advisory Council can be expanded to add/include individuals who have been diagnosed with dementia.

We know that stigma is a tremendous obstacle for individuals and families living with this disease. I personally experienced the very painful and isolating results of this in caring for both my father and my husband from 1984 to 2012. It is my personal belief that, if we truly hope to reduce stigma, improve care, and help the public fight against ADRD, we must have someone who is living with the disease on the Advisory Council.

I trust that you will act upon this recommendation and set an example for all that those with dementia continue to contribute and have capabilities, not just disabilities.

Thank you.

Lynda Everman

**DATE:** January 12, 2013

**SUBJECT:** Representation of ALS patients on NAPA

There's an old Middle Eastern saying, "If you want to know how good the medicine is, don't ask the doctor, ask the patient." I believe the same wise saying should apply to advisory committees.

For eight years I have counseled, wrote about, cared for Alzheimer's patients, and have done research in human information processing. I can attest that the perspective of someone with the disease is different from those who know the illnesses at arms length. This includes researchers, caregivers, and medical personnel.

I believe it is important to have someone on your committee who has Alzheimer's. Life as seen through any illness is different from life without it. It can provide a unique perspective to other committee members. The inclusion of Alzheimer's patients in the United Kingdom advisory committees has met with great success.

Having someone with Alzheimer's can give the committee a type of perspective that isn't possible from those without it. I suggest Michael Ellenbogen for your consideration.

Sincerely,

Stan Goldberg, Ph.D.